

Perinatal HIV Surveillance: A Tool for Targeting and Evaluating Perinatal Prevention Programs

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This morning we will present an overview of perinatal HIV surveillance and then show several examples of how state and local health departments are using their surveillance data for planning, targeting and evaluating prevention programs.

Overview of Perinatal HIV Surveillance

HIV/AIDS surveillance is the major tool used by CDC and state and local health departments to track the epidemic. Surveillance activities provide demographic, laboratory, clinical, and behavioral risk data to identify populations at greatest risk for HIV infection and to estimate the size and scope of the epidemic at the national level.

The population groups important to perinatal surveillance include: HIV-infected women, HIV-positive pregnant women, HIV-exposed infants, HIV-infected infants, infants who develop AIDS, and those exposed and infected infants who die. CDC and the Council of State and Territorial Epidemiologists (CSTE) support surveillance of perinatal exposure and HIV infection as an extension of AIDS surveillance. The American Academy of Pediatrics issued a policy statement in 1998 in support of reporting HIV exposure and infection (*Pediatrics* 1998 Feb;101(2):315-9). Collecting surveillance data on HIV-exposed and infected infants is critical to states' ability to target prevention and care resources and to the timely evaluation of perinatal prevention activities.

Reporting laws and regulations vary from state to state. Since the early 1980's, all state and local health departments have been conducting routine surveillance for perinatal AIDS. Currently, there are 36 areas that conduct named-based HIV infection reporting, and there are 9 areas that use coded identifiers for perinatal HIV reporting. Most of the states conducting HIV infection reporting also conduct surveillance on HIV-exposure in infants.

The overall objectives of perinatal surveillance activities include

- characterizing recent trends in the perinatal HIV and AIDS epidemic;
- assessing the implementation and impact of the Public Health Service perinatal prevention guidelines (HIV counseling and timely HIV diagnostic testing of the mother, the offering of antiretroviral therapy to HIV-positive women, avoidance of breast-feeding, and--for HIV infected infants--receipt of PCP prophylaxis);
- contributing relevant, scientifically-based data to assess the resource needs for prevention and for care;
- assessing prevention failures or missed prevention opportunities; and
- contributing data to help target and evaluate the effect of prevention efforts and activities.

In order to meet these surveillance objectives, a combination of both routine and enhanced surveillance methods are used:

- routine perinatal surveillance
 - population-based
 - active and passive case ascertainment
 - follow-up of exposed infants
- enhanced surveillance methodologies
 - enhanced case ascertainment
 - multiple sources of data
 - more complete and additional data
- collaboration with HIV prevention, MCH, other perinatal surveillance, and substance abuse programs.

In 1996, the routine perinatal surveillance system was expanded and enhanced methods were instituted in 7 states. These areas collected enhanced perinatal surveillance data for infants born in 1993 and in 1995-1997. Because of the completeness and quality of these data, they were instrumental in demonstrating the rapid implementation of the PHS guidelines and the success of voluntary testing for HIV in preventing perinatal infections. In late 1999, the enhanced surveillance methods were expanded to include 22 states and 4 cities most affected by the perinatal epidemic.

In all areas funded for enhanced surveillance and in many other states as well, perinatal surveillance staff have either begun or have increased collaborative efforts with HIV prevention, Maternal and Child Health, other perinatal surveillance (e.g., Group B Strep, syphilis), and substance abuse programs.

Since 1995, data collected through routine surveillance have included mother's HIV status, the timing and number of prenatal care visits, receipt of antiretroviral therapy (prenatal, intrapartum, and neonatal), type of delivery (vaginal versus c-section), and the occurrence of birth defects. To supplement these data, enhanced perinatal HIV surveillance collects data on:

- more specific details of timing and receipt of prenatal care, birth history, and combination ART
- maternal and infant disease screening
- maternal reproductive history
- maternal drug use and STDs during pregnancy
- rapid testing at delivery
- antiretroviral resistance testing in infant
- assessment of maternal and infant care.

Project Sites

Twenty-six project areas in 22 states receive funding for enhanced surveillance: Alabama, California, Chicago, Connecticut, District of Columbia, Florida, Georgia, Houston, Los Angeles, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, New Jersey, New York State, New York City, North Carolina, Ohio, Pennsylvania, Philadelphia, Puerto Rico, South Carolina, Tennessee, Texas, and Virginia. Some of these sites receive funding for both perinatal prevention and enhanced surveillance. The states of Illinois (outside of Chicago) and Delaware receive funding only for perinatal prevention.

For those areas that will be conducting enhanced surveillance using named HIV exposure and infection reporting, ascertainment of mother-infant pairs will be accomplished using:

- active case finding at pediatric sites and OB hospitals

- matching of HIV/AIDS registry to birth registry
- case reports of women pregnant at time of report to health department
- laboratory reporting – if not already being used as a routine part of case finding.

For those areas that do not currently have HIV exposure and infection reporting or will be conducting enhanced surveillance using unique coded identifier (versus a name), ascertainment of mother-infant pairs will be accomplished using facility based IRB-approved protocols. For example, names will remain at the facility and a study-assigned identification number will link the records at the facility to the record in the surveillance data base and will allow for linking of the mother and the HIV-exposed child. Data will be collected from both the mother's and the child's medical records. To try to ensure that the data are representative, facilities with the largest number of births to HIV-positive women will be selected.

Many of these project areas will also be collaborating with other programs (e.g., Pediatric Spectrum of Disease project, Medicaid) to identify mother/infant pairs and will be able to obtain data from mothers' and infants' medical charts. In addition, perinatal AIDS case reporting, which continues at all sites, will provide areas with a population-based approach to determining reasons for prevention failures. And over the next few years, those areas that do not have HIV exposure and infection reporting will be working toward implementation of reporting either by name or unique code.

All states that have been collecting both routine and enhanced surveillance data have also been looking at data to assess and evaluate prevention efforts aimed at each stage of the cascade of services. The state and local areas have been specifically looking at indicators to determine both prevention successes and missed opportunities. For example, they:

- assess the proportion of mothers of HIV-exposed children who received prenatal care;
- assess the proportion of these mothers who were:
 - counseled about HIV
 - offered and accepted HIV testing
 - offered and accepted ART;
- determine rates of c-section for HIV prevention and of abstinence from breast-feeding;
- assess prevention failures; and
- assess impact on perinatal transmission rates.

Examples of State/Local Uses of Perinatal Surveillance Data

New Jersey. New Jersey conducts HIV-exposure and infection reporting, by name, statewide. It was one of the original 7 states that implemented enhanced surveillance methodologies and has enhanced data beginning with the 1993 birth cohort. Comparing surveillance data to data from the state-based Survey of Childbearing Women (SCBW) demonstrates that from 1993-1998, surveillance data have been very complete (80%-90%). Surveillance data for 1999 are less complete at this time due to a delay in the birth registry match, which is an integral part of enhanced perinatal surveillance.

New Jersey has used SCBW and enhanced surveillance data to target prevention interventions to African American and Latino women residing in Newark, Jersey City, and Paterson. The data show that African American women of childbearing age have a rate of HIV infection 13 times greater and Latino women have a rate 8 times greater than that for white women. Additionally, surveillance staff have

assisted their prevention staff in data base development, specifically for evaluation of outreach and referral activities and continual assistance in the guidance of local prevention programs.

New York City. Since 1988, the New York State Department of Health has tested all newborns for HIV. From 1988 through January 1997 this was done as a blinded serosurvey. Since February 1997 the testing has been conducted through the statewide mandatory newborn HIV testing program. Since 1989, pediatric HIV-exposure and infection surveillance in New York City has been facility-based, conducted at 22 sites using IRB-approved protocols. In June 2000, New York State implemented named HIV-infection reporting for adults and children.

Comparing serosurvey data to surveillance data demonstrates that completeness of surveillance reporting has improved over time and, in 1998, 74% of NYC births were identified and reported from the 22 pediatric sites that participated in Pediatric HIV Surveillance Projects (1999 surveillance data are incomplete at the time due to routine reporting delays).

Philadelphia. Philadelphia has conducted HIV-exposure and infection surveillance based on voluntary reporting by health care practitioners. Recently, however, Philadelphia passed a resolution requiring reporting of HIV-positive women and their HIV-exposed infants, by name, to the city health department.

Philadelphia uses surveillance data to describe the perinatal epidemic geographically. The distribution of female AIDS cases by zip code of residence at diagnosis and the distribution of voluntarily reported perinatal HIV-exposures are plotted onto a map. These data are very useful for prevention planning and could be used over time to help evaluate prevention programs, for example, social marketing campaigns targeted to particular zip code areas.

The University of Pennsylvania, Drexel University, and the Philadelphia Department of Health worked collaboratively on an analysis of surveillance data that was presented this month at the Retroviruses and Opportunistic Infections Conference in Chicago. They reported on 250 births to HIV-infected women in Philadelphia between 1994 and 1998. In a logistic regression model, receipt of inadequate prenatal care and black race were significantly associated with failure to receive prenatal antiretroviral therapy during pregnancy.

The authors then characterized mothers who did not receive prenatal care. Factors shown to be associated with lack of prenatal care for these HIV-infected pregnant women were: injecting drug use or unidentified risk for HIV, non-Hispanic ethnicity, smoking, and use of alcohol.

As the authors concluded, efforts to characterize barriers to obtaining adequate prenatal care and to understand racial disparities in receipt of prenatal antiretroviral therapy are crucial to prevention program planning.

Los Angeles. Because California does not have HIV infection reporting, enhanced perinatal surveillance in Los Angeles County is conducted using a facility-based approach with IRB-approved protocols. Project surveillance staff worked in collaboration with staff from the Pediatric Spectrum of Disease (PSD) project. Based on PSD data, the sites chosen for facility-based enhanced perinatal surveillance report about 97% of all prenatally-exposed cases. PSD data show there has been an increasing use of maternal ZDV and decreasing rates of perinatal HIV transmission from 1995 through 2000.

South Carolina. South Carolina conducts name-based HIV-exposure and infection reporting statewide.

State-wide trends in cesarean-section deliveries for HIV-exposed infants were assessed. In South Carolina the trend towards an increasing proportion of c-section deliveries mirrors the nationwide trend. However, the proportion of deliveries by c-section is variable by state – with some states seeing no increasing trend. This same analysis can be done looking at specific hospitals within a state. This local level data can be used for data quality assurance measures and to document areas to target for further prevention efforts and/or to help evaluate previously implemented activities.

Michigan. Michigan has name-based HIV infection and exposure reporting and was another of the original 7 states to conduct enhanced perinatal surveillance (birth years 1993-1998). Enhanced perinatal surveillance data have enabled Michigan health department staff to document progress toward the elimination of perinatal HIV in Michigan (*MMWR* article in press):

- trends in maternal and neonatal ZDV (1993-1998)
 - significant increases in maternal and neonatal ZDV use
 - very few women refused ZDV
- missed prevention opportunities
 - all HIV-positive infants had some contact with health care system
- factors associated with no or inadequate prenatal care
 - illegal drug and alcohol use more frequent in women with the fewest prenatal care visits
- compliance with Michigan counseling and testing laws
 - requires HIV counseling and testing of pregnant women unless the women does not consent to testing
 - high proportion of practitioners comply, but some missed opportunities for counseling, testing, and prevention therapy.

New York City. The Pediatric Unit of the Office of AIDS Surveillance in New York City publishes a semi-annual report which focuses exclusively on the perinatal epidemic in NYC. The report includes data on perinatally exposed and HIV-infected children. The report highlights data from HIV-exposure, HIV-infection, and AIDS surveillance, the Pediatric Spectrum of Disease Project, vital statistics on HIV/AIDS related mortality, and the NYS Newborn Testing Program. The report is available on the internet at www.ci.nyc.ny.us/html/doh.

These are just some examples of how surveillance data are being used and disseminated. Perinatal surveillance data are also being used by Community Planning Groups and have been incorporated into many states' Epi Profiles, HIV/AIDS Surveillance Reports, HIV/AIDS slide sets and web sites, and many other types of publications used by local prevention planning groups.

Conclusion

In conclusion, surveillance data can be used for targeting prevention efforts to specific populations for maximal reduction in perinatal prevention. Surveillance data need to be able to identify women at risk for HIV infection, HIV-positive women at risk for becoming pregnant, HIV-positive pregnant women who need prenatal care and other medical and social services, and HIV-exposed infants. Specific prevention interventions can be targeted towards each of these populations.

Collaboration between prevention, surveillance, and other programs targeting women and children results in the best use of limited resources, avoids duplication of efforts, allows for coordinated services to women, and points to more opportunities to encourage women to know their HIV status--ideally

before pregnancy but, if not, then early in pregnancy.

Many areas have established perinatal prevention working groups or task forces consisting of staff from prevention, surveillance, health services, STD, and Title IV programs within the health departments. Also included may be staff from HIV/AIDS education and training units, local community-based organizations, as well as local care providers.

The surveillance data being collected should be pertinent to HIV prevention efforts, address prevention program needs, be responsive to changing needs, and should be disseminated in a timely way to all those involved in planning, targeting, and evaluating prevention efforts.

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